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ABSTRACT

This monograph describes how to conduct simulations that allow individuals to experience what it is like to have deafblindness. It begins by discussing the philosophy and benefits of simulations and explains the two different types of simulations. The first type of simulation gives a generic overview of the impact of deafblindness on learning and gathering information about the world. The second type is designed to increase understanding regarding the needs and experiences of a specific individual. Limitations of simulations are also addressed. The next part of the monograph discusses safety issues and planning a simulation experience. The contents of a basic simulation kit are listed, and initial instructions for providing a simulation experience are provided. The final part of the guide describes different types of simulation activities that include communication/language activities, large group activities, concept development activities, daily living skills, social skills, vocational skills, and leisure and recreation activities. A list of thoughts about simulations from the perspectives of intervenor and participants is provided, along with a simulation outline and a resource list. (CR)

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Practical and Creative Simulations For Training Personnel in Deafblindness

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&
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Creative Simulations in Deafblindness

Joyce Olson & Jennifer Grondin

Excerpts from Our Journals

Karen Bourel writes:

We started the morning off with a simulation, half the group taking the part of Intervenor, while the other half experienced, to a degree, the world of the deafblind person. After a period of time the roles were reversed to give everyone a taste of both sides.

As an Intervenor I ran through a full gamut of emotions. I felt I had been plunged in at the deep end: frustration, inadequacy, a feeling of helplessness, were all there on the surface. How do I identify myself to this person, how do I win her trust? Tactile cues were my only means of communication, but how would I know what she was feeling, needing, wanting? To meet her needs and communicate our task seemed an insurmountable assignment. As we began she seemed hesitant, probably sensing my inexperience and frustration. When we started working together I sensed that trust was growing as I felt her touch on my arm relax to some extent. At the completion of our goal, a smile on her face let me know she felt good about her accomplishment.

Next it was my turn to take on the role of a deafblind individual. I found this to be "scary". I felt abandoned, isolated, vulnerable and totally without control. I came to dread the footsteps that brought new assaults each time they came near. Finally my Intervenor arrived. She let me know who she was by touch. She was gentle and patient. She carefully led me outside. I felt safe and was able to walk along easily. She showed me many things in my small, dark, quiet world. She guided my hand to many objects and handed me others. (I didn't understand we were on a scavenger hunt and that I was to collect these items to complete a goal!).

These simulations although very draining were definitely the highlight of the day. The lessons learned are something that will live with me for many years to come. Today I had my first real glimpse into the world of the deafblind. I had no idea how little knowledge I possessed in this area. I don't think I ever understood just how isolated their world is, and what a difference an Intervenor can make.

Margo Hanson writes:

The highlight of today was definitely the simulations. Never before have I felt so small and inadequate both as an Intervenor and as a person with deafblindness. I have tackled lots of things in my life that were new to me, but I must say this has got to be the most foreign.

I think the biggest surprise was the fact I totally reverted back to basic instincts and emotions. The emotions I felt today came on so fast and strong that there was no time to suppress them and once unleashed I felt savage. Keep in mind I am a take charge kind of person and I was powerless against my own reactions. They surprise me now even hours later.

I thought I knew what an Intervenor did, but it's so much more than I anticipated. I have been told what Intervention is but to experience it first hand, I now realize it was all words. I can't believe how superficious my ideology of this concept was.

Philosophy of Simulations

There is nothing more powerful or moving than a well done simulation. Nothing we can tell people about deafblindness can measure up to personally experiencing an activity with limited visual and auditory input. It has been our experience that it is the simulation people remember; it is the one thing that people will keep referring to again and again as they learn more about deafblindness. As facilitators, we have a responsibility to provide the best simulation possible to spark people's interest and to help them come to a better understanding of the challenges that a person with deafblindness faces each moment of every day. Simulations are done to get people thinking about what it means to experience the world when we can not rely on our vision and hearing for accurate information. Deafblindness is essentially an information gathering disability; nothing drives this point home faster than an effective simulation.

We use two types of simulations to help people better understand the critical role our distance senses play in providing us with information. The first gives a generic overview of the impact of deafblindness on learning and gathering information about the world. The second type is designed to increase the understanding regarding the needs and experiences of a specific individual. In the first scenario, we use a standard set of activities designed to emphasize certain points, such as the difficulty a person with congenital deafblindness may have in developing formal communication strategies, the inherent lack of motivation in many activities, and the critical role the Intervenor plays in providing information in a meaningful way.

In the second type of simulation, it is important that you take the time to observe the person with deafblindness, the people interacting with that person and the activities they are engaged in. Through such observations you will be able to plan effective simulations that are tailored to the message you wish to convey. For example, if you are training people who are working with a child in kindergarten, plan activities that are common in that setting. Some of our favourites are finger painting with chocolate pudding, doing a show and tell and/or circle activity, or perhaps telling a story. These activities would be very inappropriate to simulate the life experiences of a young adult. In this case we would plan vocational activities such as assembling sets of plastic cutlery with a napkin, or any activity that you have observed the young adult doing. The goal in this type of simulation is to help the participants learn how they can better support an individual; what better way to do this than by having them experience the same activities they are asking the person with deafblindness to do. The activities you do in a simulation are only limited by your creativity and imagination. We enjoy the planning of the simulations as much as facilitating them - no two are exactly alike.

Cautions

Many people will argue that simulations create a false impression. They are not real. There is no way we will ever be able to experience what the world is like for someone who is deafblind. This is very true. Our intent in doing simulations is to get people thinking, not to recreate the experience of someone who lives each day with deafblindness. We can not possibly do this, and as facilitators we need to be very up front about this. We start every simulation by saying this experience is not real, this not the way the person you support experiences their world. For one thing, each participant brings to the simulation a wealth of background information that someone who has never seen or heard may not have. Another important point is that we are so used to relying on our distance senses to gather information, that it comes as a shock to suddenly have those senses taken away. Many of us react more intensely to the situation, than someone who has never seen or heard. Relying on other ways of gathering information is a natural way of being for the people we support, but can be very frightening for someone under simulation. The simulations are also misleading in that we know we can take the blindfolds off in 20 or 30 minutes; it tends to make us more patient and willing to put up with what is happening.

Having said all of these things, we still believe that simulations are important in helping us better understand how we can improve our interactions with someone who is deafblind. The simulation should be a starting point for further discussion. It is not an experience that can be rushed through and then left for people to figure out on their own. The discussion afterward is equally as important as the simulation itself. It is in the follow-up discussion that you will be able to correct any misconceptions that may have occurred, and share information about Deafblindness and the techniques of Intervention in a way that people will remember.

Simulations for Congenital and Adventitious Deafblindness

It is important to help the participants understand the different needs of these two groups. People who have lost their vision and/or hearing later in life have a strong language base and therefore their needs are quite different from people who were born with deafblindness and may have a more limited experience with the world. Most of the examples suggested in this presentation are geared toward the experiences of someone who has been born with both visual and auditory impairments. If you are interested in helping people get a better sense of the needs of people with adventitious Deafblindness, I would recommend you work with someone from the adult deafblind community and let them explain their experiences directly.

Responding to the Needs of the Participants

As facilitators, we have to be very sensitive to our participants' needs. Many people will experience deep emotions. I have seen people react with tears, anger, withdrawal, aggression, nervous laughter, apathy, passive responses, some report enjoying the quietness and the time to reflect inwardly. Many may develop physical symptoms such as headaches or upset stomachs. Watch for signs of anxiety in the participants and allow individuals to stop if needed. Never force anyone to participate. A good facilitator watches for these reactions and does what is possible to make the experience a positive one for each person. Don't be afraid to modify your plan as you go.

Observe the participants' reactions and make mental notes of examples that can be used to highlight certain points you wish to make later in the discussion. Use these reactions to point out the similarities or differences that someone with Deafblindness may demonstrate in similar situations. For example, point out that most of the people we support have been born with their dual sensory impairment, that is the only way they know how to relate to the world and they may react differently than we would in the simulation.

Remember our goal is to get people thinking, not to recreate the world of someone who is Deafblind. Use the simulations to draw parallels wherever possible and to get them thinking in terms of how can they better support a person with Deafblindness. For example, if someone reacts by withdrawing from the situation, or by getting frustrated or angry, ask them why they reacted that way, what was it like for you. Do you think the person you support might feel that way sometimes? What would have made it easier for you in this situation? Do you think that would work for the person you support? How could you get the person you support to be more actively involved?

During the discussion, people may react with a variety of responses. A common response is guilt, "What have I done to the kids I have worked with all these years? I didn't know what it was like!". Another common response is anger, "How could you do this to me? It was awful; you treated me very unfairly. I would never do that to someone I support.". Fear of being humiliated is also common, "I'm the only one doing this and everyone is laughing at me". Remember that people bring their own personalities and past experiences into the simulations and their responses will be as varied as their personalities. Be sensitive to these responses and address them. If one person is voicing this response, there will be others there with similar reactions and they need to have the opportunity to talk about them.

Safety

It is important to ensure the safety of all the participants. Choose activities that will not put people at risk. In one of the early simulations I facilitated years ago, I set up an obstacle course in the gym. My intent was for people to crawl under the table, but I did not make my instructions clear enough. One Intervenor took their "Deafblind person" over the table and it collapsed. Fortunately, no one was hurt, but I learned a very valuable lesson as a facilitator. Safety has to come first in all simulation exercises. In a simulation, people who are used to relying on their vision and hearing are suddenly forced to use their other senses, but do not have the conscious experience of moving safely through the environment. As facilitators we have

a responsibility to avoid potentially dangerous situations, and during the simulation itself, to be constantly monitoring the participants to make sure they are safe.

There are a number of things we can do in our introduction to the simulation that will enhance the participants' experience and ensure their safety. Always ask if there is anyone in the group who has any allergies and then modify the experience accordingly. For example, it would be very dangerous to make peanut butter sandwiches with someone who has a severe allergy to peanuts, or to force someone with a latex allergy to play with balloons. This is information you need before you begin. If the activity can't be modified, then let the person sit out with the blindfold on, or have their Intervenor take them for a walk.

Always stress that during the simulation the person without the blindfold is totally responsible for the safety of the other. Review proper sighted guide techniques with the whole group. If there are stairs or other obstacles, that must be used in the simulation, make sure people know how to navigate them safely with the blindfolds on.

Planning a Simulation Experience

Goals:

The first step is to decide what you want your target group to get out of the simulation. One of the main goals will always be to get people thinking about Deafblindness and its impact on how a person gathers information, learns, and communicates. More specific goals can also be included when there are certain points you want people to learn about an individual, or about Deafblindness in general. Once you have determined what you want people to learn from the simulation the rest flows easily. If the activities reflect your goals, the participants will generate the information you want with very little prompting.

Materials:

Be sure your materials reflect your goals. Are they appropriate for the points you are trying to convey? Do they match the age group you are addressing in your simulation?

Be organized. Have your materials ready in easily accessible carrying cases. Group materials according to activity, so you can pull out what you need for each activity quickly and easily.

The element of surprise is important to a successful simulation. Keep your materials out of sight until the participant have their goggles or blindfolds, and earplugs in place.

Basic Simulation Kit:

It is useful to keep a set of basic supplies on hand. We would suggest the following materials should be part of your simulation kit:

- blindfolds (sleep masks work well)
- visual impairment simulation goggles
- foam earplugs
- a box of crackers (small bite size)
- a box of Kleenexes
- pre-moistened wipes (Wet Ones, Handi-Wipes, etc.)
- scent vials
- an assortment of plastic fruits, vegetables, small toys, etc.
- parachute, small balls such as nerf balls, tennis balls etc.
- tissue paper for crafts, yarn - precut into sizes needed for craft activity
- chart paper - scented markers
- any materials you use in your simulation activities on a regular basis

Initial Instructions:

Set the stage. Give some background information about your goals for the workshop, a brief introduction to Deafblindness as a unique disability. Deafblindness is essentially an information gathering disability. Talk a bit about the role our senses play in gathering information, then invite the participants to join you in a simulation experience to gain a better understanding of the role our senses play. Let the participants know what to expect, without giving away the activities.

Ask if anyone has any allergies and take careful note of the responses.

Have the participants choose a partner and let them decide who will be "Deafblind" first and who will be the Intervenor. Explain that everyone will get a turn in both roles and they will be trading half way through the simulation.

Set the rules for the simulation. This will vary depending on the type of simulation you intend to do. For a generic simulation, we usually explain that a hearing impairment is very hard to simulate. We use the ear plugs to muffle sound, but they may represent a mild to moderate hearing loss at best and are not really very effective. For this reason we ask the participants to refrain from using their voices. We tell them we are taking them back to a point before they had any formal language and ask them not to use sign language if they know it. They may communicate through touch and gesture.

At this point, emphasize the importance of the Intervenor's role in keeping the person they are with, safe and out of danger. Demonstrate proper sighted guide techniques, and point out any other safety issues that may be unique to your location.

Timing:

It works best if you have two facilitators - one to talk to the people who will be Deafblind and another to prepare the people who will be the Intervenors. (It can be done with one facilitator, it just takes longer as you talk with each group separately). Have the people who have chosen to be Deafblind stay where they are, while the people who will be the Intervenors go into a separate room or down the hallway (out of earshot of the first group).

Group 1 - People under Simulation

One of the facilitators stays with the first group and explains that as soon as they have their blindfolds on and the earplugs in, they are "Deafblind" - no more voice or sign to communicate, gestures and touch are fine. Their instructions are to wait for their Intervenors to come and get them. While they are waiting in the large group turn a television set on with just white noise playing in the background. This is the facilitator's chance to let the participants experience how important our distance senses are in anticipating what is happening and communicating with others. "Entertain" the group while they wait with a variety of activities such as a snack - pop a cracker in the person's mouth with no warning, then wipe their hands with a wet handi-wipe to clean up. Do a little activity with each person, like letting them smell a scented vial that contains a scent that is out of context for the situation (perhaps cinnamon, or lemon without having the real object present), or bring in a puppet and tickle each person's arm. Be sure to reward people for good behavior with a firm pat on the shoulder. Move quickly from one person to another and do not spend too much time with any one individual. In this portion of the simulation, the element of surprise is essential.

This part of the simulation should not take anymore than 5 minutes. Invariably, when you ask people how long they were waiting, they will report it seemed at least 15 to 20 minutes, an eternity in some cases. In the discussion afterward be sure to point out how different your sense of time is without input from your vision and hearing!

Group 2- Intervenors

The second facilitator takes the group who will be the Intervenors to a separate space and explains the activities to them. Explain that it will be their job to teach the "person with Deafblindness" how to communicate and to make the experience as meaningful as possible. Keep your instructions brief and to the point. Let the participants work out how they will explain the activities to the person they are supporting. Pass out any materials needed for the activities (eg. plastic food for the language simulation, parachute materials for group activity simulation).

If you are facilitating alone, get the first group set up with their blindfolds and earplugs, while they are putting them on, go to the second group and explain the activities. Give them time to discuss how they will communicate and do the activities, while the facilitator goes back to the first group and entertains them with the activities mentioned above.

Activities:

The activities you choose to do should match the goals you have set for the simulation. If most of the participants are working with young children choose your simulation activities accordingly. Let the people in your session experience how much fun show and tell can be with limited vision and hearing, or perhaps storytime, or the monthly calendar at circle time. A particular favourite of ours is finger painting with cold pudding (We add rice half way through for a variety in texture, without any warning of course). If the people you are teaching work with adults then plan a work experience activity, such as sorting and assembling plastic cutlery for fast food outlets.

Examples of Activities

1. Communication / Language Activities

   a) Teach a new language of touch cues. Have the Intervenor come up with 4 different touch cues - a name sign for themselves, a name sign for the person they are supporting, and 2 touch "words" for 2 plastic toys. Distribute pieces of plastic fruit and vegetables to each of the Intervenors, then have them teach this new language to the the people under simulation.

   b) Use the goggles and have each team order a pizza from a poorly printed menu.

   c) Administer the spelling test from *Sound Hearing, Or...Hearing What You Miss*

2. Large Group Activities

   a) Parachute games in a large open space

   b) Dodge Ball

   c) Pass the "Hot Potatoe" game

3. Concept Development

   a) Flower Unit - Explore a variety of plants and flowers. Tell the Intervenors to teach as much as they can about flowers in a 10 minute period (without words). Make a tissue paper flower.

   b) Make a tactile alphabet - glue macaroni, rice, etc. on large letters, cut them out and make words with the whole group.

4. Daily Living Skills

   a) Simple cooking activities - make a sandwich, decorate cupcakes, mix some juice.

   b) Sort clean laundry into similar articles, fold the towels and washcloths.

   c) Brush someone's teeth for them.

   d) Eat lunch.

   e) Make a bed.

5. Social Skills

   a) Prepare for a dance, make popcorn, hang decorations, make punch.

   b) Share a finished craft with another person under simulation.

   c) Have a Halloween party, complete with a haunted house.

   d) Do a tactile ice breaker, such as finding the person who is wearing the same bracelet you are.

6. Vocational Skills

   a) Sorting and Assembly tasks.

   b) Code file folders with tactile cues. File in section marked with the same cue.

   c) Pack and tape a box.

7. Leisure and Recreation

   a) Scavenger hunt - ex. collect 3 sheets of toilet paper, 2 smooth stones, a feather, 4 different types of leaves, and a clover leaf.

   b) Craft Activities - make a tissue paper flower, or a butterfly.

   c) Play a game.

   d) Fly a kite.

Recording:

It is important that people have a chance to record their thoughts, feelings, and experiences as a Person with Deafblindness and as the Intervenor immediately after the simulation. Have chart paper and pens available for each group (you will need 4 different sets - 2 for the people who were under simulation and 2 for the Intervenors).

Example of Thoughts from Participants:

How did you feel as an Intervenor

- Wanted to over protect.
- Wanted to stimulate the deafblind person more.
- Wanted to be able to communicate better.
- Responsible to "fill in" time for the DB person.
- Was frustrating - would be easy to do everything for her.
- Was hard to put across exactly what experience we were undertaking.
- Felt like it was a betrayal to take a different person - someone they didn't know or trust.
- Frustrated with not having more ways to communicate.
- I would like to have known the activity and the time frame before trying to introduce it to the deafblind person.
- Unable to explain all that others were experiencing so quickly.
- Felt very inadequately

How did you feel as a person with deafblindness

- I felt I was unable to express my need for better direction from my Intervenor.
- Frustrated when switched task before completing first one.
- Very worried when first contact was something being put in my mouth.
- Repetition important and needed feedback.
- Needed/wanted to be touched.
- Was enjoying the sun and warmth when someone tried to put something in my mouth -- didn't like the intrusion.
- Didn't like smell of icing, or hot air blowing on me when coming in to building.
- I couldn't wait to get the blindfold off!
- Isolated. Time was very long when left alone.
- You had to develop confidence in your companion.
- Lonely and couldn't make sense of what was expected of me.
- Scared - when my first "guide" left me - and someone took over for her.
- Scared - when left alone outside
- Scared by touch from "nowhere"
- appreciated positive feedback - hand squeeze.
- encouraged by pats on shoulder.
- Ground seemed so uneven from grass to gravel to pavement.
- Startled by all the unfamiliar touching and prodding.
- I was freezing outside - didn't know how to communicate this.
- When left alone, I didn't know what to do next. What was expected! Long time!! Anxious -fearful when not touching someone.

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Discussion:

Talk about the responses the participants have recorded. Use them to draw out the points you want to make about Deafblindness. This can be done in a number of ways, such as talking about each point individually and getting the person who wrote it to elaborate, or summarizing the points and grouping them into themes such as issues that arose around anticipation, communication, motivation, and confirmation.

Follow-Up:

How does this apply to the person you are supporting? Where do you go from here?

Sample Simulation

Goals

1. The learner will gain an understanding of the role the eyes and ears play in gathering information about the environment.
2. The learner will gain an understanding of how difficult learning a formal communication system can be, and how the ability to communicate impacts on all activities and social exchanges.
3. The learner will gain an understanding of the impact Deafblindness has on the person's ability to anticipate what is happening, on the motivation inherent in an activity, and on understanding the results of the person's actions on the environment.
4. The learner will develop a greater appreciation for the role of the Intervenor and the challenge of ensuring that the person with Deafblindness is an active and informed participant in any activity.

Simulation Outline

05 min. **Introduction to the Day**

- discuss goals
- audience goals

10 min. **Introduction to Deafblindness**

- deafblindness is a unique disability
- senses
- distance vs. impact senses
- information gathering disability
- congenital and adventitious deafblindness

20 min. **Introduction to Simulation**

- choose a partner, decide who will be under simulation first
- sighted guide techniques / safety issues
- only able to simulate a mild to moderate hearing loss
- no voice, no formal sign, no print on palm

30 min. **Group 1 Simulation**

1. Have the first group to be "Deafblind" stay in their seats and direct the "Intervenors" to a different room or area to receive their instructions.
2. Once the first group has their blindfolds and earplugs in they wait, with facilitator-directed activities as described earlier.
3. Intervenors rejoin the people under simulation.

Activity 1 - Language Simulation

1. Intervenor introduces them self without using voice, teaches the person their name sign, and the name sign of the person they are working with.
2. The Intervenor now teaches the "Deafblind" person two new words using a language of touch, to identify 2 objects they have brought with them.
3. The Intervenor tries to engage the person in a conversation by asking them what they had for breakfast that morning.

Activity 2 - Large Group Simulation - Parachute Games

1. Go to large open area for parachute activities.
2. The participants unroll the parachute and get in position around the edges. Wave the parachute a few times to get the feel of it.
3. Have everyone make a mushroom with the parachute - everyone lifts at the same time and traps the air inside as they pull the edges to the ground. Do this 3-4 times.
4. Play popcorn : bounce small soft balls on the parachute while the group is moving the parachute in an up / down motion. The balls create a popcorn effect.
5. Walk in a circle to the left holding the parachute taut, then walk to the right.
6. Have the whole group put the parachute and balls away.

15 min. **Transition Activities**

1. The facilitator takes each person under simulation away from their Intervenor and leads them to a safe place touching a wall or other stable object or sits them on a chair or on the grass and walks away leaving them on their own.
2. Signal to the Intervenors to return to the original classroom area.
3. Help the people under simulation remove their blindfolds.
4. Keep two groups separate and have each group write their feelings, thoughts, and reactions to the experience.

30 min. **Group 2 Simulation**

1. The first group of Intervenors will now have a turn to be under simulation. Pass out the blindfolds and earplugs and as soon as the group is ready let them wait. Repeat the facilitator-directed activities as with the first group.
2. The people who were"Deafblind" will now be the Intervenors.
3. Explain the second set of activities to them and what they are to do.
4. Intervenors rejoin the people under simulation.

Activity 3 - Daily Living Skills Simulation - Cooking

1. Intervenors introduce themselves.
2. Make a peanut butter and pickle sandwich together (or ice and decorate cupcakes, or spread soft cheese on crackers).
3. Put whatever you have made on a paper plate with your name on it and set it aside for later (It is important that it is not eaten right away to get across how hard this can be to understand for someone who is Deafblind and may not like to wait).

Activity 4 - "Understanding the Abstract" Simulation - Flowers

1. Intervenors take the person they are supporting on a nature walk to explore different plants and flowers. (If the setting does not allow for this, bring in some cut flowers and plastic flowers to explore). Instruct the Intervenors to teach as much as they can about plants and flowers in 10 minutes.
2. Return to classroom and make a tissue paper flower together.
3. Share the finished flower with another team, and exchange flowers with your new friend.

15 min. Remove blindfolds. Break time - finish writing feelings, thoughts and emotions

45 min. Discussion of feelings, thoughts, emotions, and key points of sensory deprivation

Resource List

Low Vision Simulation Kit - George J. Zimmerman, Ph.D., University of Pittsburgh, 4F29 Forbes Quadrangle, Pittsburgh, PA 15260 (412) 624-7247, or 1932 Woodside Rd., Glenshaw, PA 15116-2113 (412) 487-2818

Sleep Masks - Many airline companies will donate sleep masks when you explain what you use them for.

Ear Plugs - The AEARO Company, 7115 Tomken Road, Mississauga, Ont. L5S1R8 (905) 795-0700 has been very generous in donating hearing protectors.

Sound Hearing, Or...Hearing What You Miss, Garlic Press, 100 Hillview Lane #2, Eugene, OR 97401, ISBN 0-931993-26-1 (This is an excellent audio cassette that helps give an understanding of how we hear and then offers examples of simulated hearing loss. I like to give the spelling test with the simulation goggles on!)

"What is It? / Vision is More than 20/20 Eyesight" Cards, Optometric Extension Program Foundation, Inc., Suite 3L - 1921 East Carnegie Avenue, Santa Ana, California 92705-5510 (These cards are very useful when trying to explain Cortical Visual Impairment.)